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and Beliefs in Urban Public School

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Elizabeth A. Patterson 11/14/92
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Racial Differences in Breast Cancer Screening Behaviors and Beliefs
in Urban Public School Teachers

ANNUAL REPORT -- YEAR 01 (9/15/96 - 9/14/97)

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Racial Differences in Breast Cancer Screening Behaviors and Beliefs in Urban Public School Teachers

ANNUAL REPORT -- YEAR 01 (9/15/96 - 9/14/97)

INTRODUCTION

A. Overview

Breast cancer is the leading cause of cancer mortality in African-American women (Boring, Squires & Heath, 1992). Studies in the United States in the last twenty years have reported that African-American women with breast cancer have a higher mortality rate than White women. In addition, African-American women are more likely to be diagnosed at a later stage of the disease than White women. Although recent (1989-92) mortality data from the National Cancer Institute Surveillance Program (National Center for Health Statistics, 1995) on breast cancer indicates a decrease for White women (-5.5%), the data show an increase in mortality for African-American women (+2.6%). The reasons for this difference are not entirely clear. Studies of breast cancer and race have conflicting results. Some studies of breast cancer incidence and mortality which correct for socioeconomic factors continue to show a discrepancy in data between White women and African-American women. Some studies have speculated there are differences between the races in adherence to screening guidelines, access to health care, and immediacy of diagnoses in the face of symptoms. And certain studies postulate biological differences such as types of tumor biology (Elledge, Clark, Chamness & Osborne, 1994) as the cause of mortality rate discrepancy between African-American and White women.

Unfortunately, researchers and health care professionals do not understand completely all the risk factors involved in the etiology of breast cancer. Early detection of the disease currently offers the most effective breast cancer control, and efforts rely on routine screening mammograms, clinical breast exams, and breast self-examination. A number of national and international studies offer convincing evidence that regular screening mammograms for women 50 years and older lead to a reduction in breast cancer mortality (Shapiro, Venet, Strax, Venet & Roeser, 1982). Despite this information, screening mammography is not widely utilized and African-American women are less likely than White women to avail themselves of the benefits of screening mammography. This is most often attributed to lack of education, lack of access, and low socioeconomic status. However, the issue of racial differences in breast cancer is not solely confined to the poor. It has been repeatedly shown that when socioeconomic, educational, and logistic barriers are minimized, African-Americans continue to underutilize these screening procedures (Michielutte & Diseker, 1982).

This study is being undertaken to better understand the differences between African-American and White women in breast cancer screening behaviors and the beliefs that influence those behaviors. In addition, this study will examine the factors that influence these women to undergo breast cancer screening. This study will select a defined, representative population of similar education, health care access and socioeconomic status. Data will be collected through a questionnaire distributed to study participants.

The study population is composed of female teachers (members of the Philadelphia Federation of Teachers union) over the age of 40 from the School District of Philadelphia. Approximately 37% of these 6,700 teachers are African-American. The screening behaviors and beliefs of this group should provide insight into the differences in breast cancer screening behaviors between African-American and White women. The results of this study will lead to the development of interventional programs for improvement in adherence to the accepted screening guidelines.

B. Background and Significance

Racial differences in breast cancer incidence, mortality and survival

Breast cancer is a growing problem in the United States. Nationally, the incidence has increased approximately 1% per year since the early 1970s, rising from 82.4 per 100,000 women to 108.8 cases per 100,000 women in 1990 (Hankey, Brinton, Kessler & Abrams, 1993). The American Cancer Society estimates there will be 183,400 new breast cancer cases in 1995, and 46,240 deaths from the disease. Statistics related to breast cancer incidence, mortality, and survival reveal the disparity between African-Americans and the White population. Incidence of breast cancer has increased in both the White and African-American female population, although at a higher rate among White women (Hankey et al., 1993). The increase in the 1980s, in large part, appears to be due to increases in early detection and use of mammography (Miller, Feuer & Hankey, 1991; Feuer & Wun, 1992; Swanson, Ragheb, Lin et al., 1993). The mortality rate during that same period of time shows a greater increase for African-Americans. In 1973, White women suffered 27.1 deaths per 100,000 women. In 1990 the rate was 27.4 deaths per 100,000 women. By contrast, the mortality rate among African-American women increased from 26.3 deaths per 100,000 women in 1973 to 31.7 per 100,000 in 1990 (Hankey et al., 1993). Recent (1989-92) mortality data from the National Cancer Institute Surveillance Program (National Center for Health Statistics, 1995) on breast cancer indicate a decrease for White women (-5.5%), with a continued increase in mortality for African-American women (+2.6%). Similar disparity is seen locally with average annual age-adjusted incidence in Pennsylvania for 1988-1992 of 118.9/100,000 for Whites and 107.6/100,000 for African-Americans. The mortality rates were 29.1/100,000 for White and 34.5/100,000 for African-Americans (Pennsylvania Cancer Registry, 1994).

A disturbing difference in survival rates for African-American and White women has been apparent in the United States since the 1950s (Chen, Trapido & Davis, 1994). Survival for African-Americans remains poor relative to that for Whites, with a 5-year survival of only 62% compared with 80% for Whites (Sondik, 1994). In 1983 the National Cancer Institute planned and funded the Black/White Cancer Survival Study in an effort to determine reasons for the disparity in survival between African-American and White women with breast cancer. Approximately 40% of the difference in survival was explained by more advanced disease at the time of detection and another 15% was explained by histological/pathological differences. Sociodemographic variables appeared to act largely through racial differences in stage at diagnosis (Eley, Hill, Chen et al., 1994).

Stage of the disease is the single best predictor of survival. African-American women are diagnosed with a more advanced stage of disease and have a poorer prognosis (National Cancer Institute, 1991). In Pennsylvania almost 31 percent (White 30.6%, African-American 35.4%) of females were diagnosed at the regional or distant stages of the disease in 1992. Five year survival rates are poor at these stages (Pennsylvania Cancer Registry). Chen et al. (1994) reported a significant increase in the percentage of early stage diagnoses of breast cancer during 1981-1989; however, the percentage of early stage diagnoses (in situ and local stage) was significantly lower among African-Americans than among Whites. The SEER data reveal that in 1990 only 29.8% of all breast cancers detected in African-American women were Stage I whereas in White women the percentage was 42.5% (Hankey et al., 1993).

Although racial differences in both clinical stage at diagnosis and in survival are related to socioeconomic status, the issue of racial differences in breast cancer is not solely confined to the African-American poor (Freeman & Wasfie, 1989). Studies have shown that the differences between African-Americans and Whites persist to varying degrees regardless of their socioeconomic status. Despite African-Americans' economic progress in the last three decades, they experience a continued increase in mortality from breast cancer.

Racial discrepancies in breast cancer screening behavior

Early detection of the disease currently offers the most effective breast cancer control since to date no proven technologies are available to reduce breast cancer incidence. However, studies have shown that, compared to their White cohort, African-American women utilize screening methods for breast cancer less often (Horton, Romans & Cruess, 1992). The 1987 National Health Interview Survey (National Center for Health Statistics, 1987) indicated that only 36% of women age 40 and older had ever received a clinical breast examination and mammography (38% for White women and 28% for African-American women). With increased publicity, the number of women 40 and older who have ever had a mammogram has increased. The Mammography Attitudes and Usage Study (Horton et al., 1992) shows an increase in the usage of mammography in the White population from the 1990 survey to

the 1992 survey (65% to 76%). However, there was no significant increase in the usage in the African-American population (58% to 59%).

Factors influencing the utilization of mammography among African-Americans

The majority of studies have cited low socioeconomic status combined with poor knowledge of and access to health care, lack of physician recommendation and negative psychological belief systems about cancer as the major factors that negatively impact African-Americans in their utilization of cancer screening tests.

Socioeconomic factors. Real or perceived lack of access to health care and the barriers of limited or no insurance coverage which would provide access to screening procedures are actual deterrents for disadvantaged women. For women who do not have a primary care physician and who usually obtain their health care through emergency rooms and clinics for specific acute or chronic illnesses, there is little opportunity for longitudinal care or disease prevention/health promotion activity and education.

The role of physicians. Lack of physician referral is consistently cited by high numbers of women as the reason for not obtaining a mammogram. The data suggest that mammography is not widely recommended in asymptomatic women. One study (Bloom, Grazier, Hodge & Hays, 1991) cited that only 38.8% of women over 50 recall ever being given this recommendation. When it is recommended, there was a high compliance rate (87%). Other studies report racial variations in recommending screening mammography. Gemson, Elinson, and Messeri (1988) showed that only 7% of physicians with predominately African-American and Hispanic patients recommended screening mammography as opposed to 23% of physicians with predominately White patients. Caplan, Wells, and Haynes (1992) found that African-Americans were more likely than Whites to cite lack of recommendation as the most important reason for not having a mammogram.

Negative belief systems. When the barriers of socioeconomics and lack of physician prompting are minimized, African-Americans continue to underutilize these screening procedures (National Center for Health Statistics, 1987; Rimer, Keintz, Kessler, Engstrom & Rosan, 1989). This suggests that negative health beliefs, such as fear of finding a positive result, fatalism, denial of the risk of cancer and other psychological barriers also contribute to racial differences in breast cancer screening behavior. Burack and Liang (1987), studying a predominantly African-American population, found the most commonly cited barrier to be fear of finding something wrong. Bloom, Hayes, Saunders, and Flatt (1987) also cited fear of cancer as a major barrier to cancer screening among African-Americans, and Fox and Stein (1991) found that African-Americans were more likely than Whites to report fear of cancer as a barrier. Strong fatalistic attitudes in the African-American community toward cancer and cancer treatment have been noted by various researchers (Bloom et al., 1987; Price, Desmond, Slenker, Smith & Stewart, 1992); such attitudes have been offered as a possible explanation for the fact that, among African-Americans, those who perceive

themselves to be at high risk of cancer are often less likely to obtain screening (Bloom et al., 1987; Bloom et al., 1991). Fatalism may also manifest itself in psychological avoidance of the threat of cancer. Burack and Liang (1987), for example, found that African-American women tend to place the threat of breast cancer as a lower present or future concern, in contrast to the beliefs of White women who consider breast cancer as the most worrying illness to which women are prone. Other psychological barriers that have been found to be more common among African-Americans than Whites include concerns about pain and radiation (Fox & Stein, 1991).

Advantages of studying middle and upper socioeconomic status African-Americans

Most studies of knowledge, beliefs, and behaviors of African-Americans concerning breast cancer and mammography have drawn subjects largely or exclusively from disadvantaged subpopulations (Bloom et al., 1987; Bloom et al., 1991; Price et al., 1992; Hunter et al., 1993). Nationwide, one-third of African-Americans are below the poverty level (US Census Bureau); however, there is a growing segment of improved economic status in the African-American community. The importance of understanding health behaviors of individuals with low socioeconomic status (SES) is beyond question. There is also value, however, in studying African-Americans who are of middle and upper SES. From a practical standpoint, high SES individuals tend to be accessible and open to change, and also tend to serve as role models; thus, they may serve as ideal agents of change in the African-American community. Vogel and Batiste (1992) found increased participation in a screening program by using community leaders to identify, recruit, and educate their peers about breast health. Other successful model programs utilizing African-American to work effectively in education of African-Americans have been reported (Frank-Stromborg, Johnson & McCorkle, 1987; Erwin, Spatz & Turturro, 1992). From a theoretical perspective, studies of middle and upper SES African-Americans can provide valuable information about knowledge, beliefs, values, and practices among a segment of the African-American population that has heretofore received relatively little attention in the research literature.

Beyond this, examination of middle and upper SES African-Americans should provide useful information regarding the issue of racial differences in mammography behavior. Studies have shown mammography rates among African-Americans lagging behind Whites (Jepson, Kessler, Portnoy & Gibbs, 1991; Vernon, Vogel, Halabi, Jackson, Lundy & Peters, 1992; Horton et al., 1992). Identifying the reasons for this gap, however, is no simple task. African-Americans and Whites, even if they are living in the same general geographical area, tend, to a greater or lesser extent, to form distinct subpopulations that differ in a multitude of ways. Some of these differences are objective and obvious, such as differences in income, while others are intangible and subtle, such as differences in values, cultural beliefs, and perceptions of real or perceived barriers. Identifying the factors responsible for racial differences in behavior is complex. However, the difficulty of this task might be reduced if a study could be done on a naturally-occurring, defined population containing both African-Americans and Whites, in which the nature of the population membership criteria tended to

insure comparability between the African-American and White segments on major socioeconomic factors such as income and education. Even better would be if the population were uniform in terms of health care access. Any differences in mammography behavior between African-Americans and Whites in such a population would then presumably be due largely or entirely to those intangible cultural differences between the races. The project described herein will examine such a population -- public school teachers aged 40 years and over in the School District of Philadelphia.

C. Previous studies

1. Black-White Differences in Cancer Prevention Knowledge and Behavior (Christopher Jepson, Larry G. Kessler, Barry Portnoy, and Tyson Gibbs)

This study was an analysis of data from the 1987 National Health Interview Survey Cancer Control Supplement. Among African-American women aged 40 and over ($n = 907$), 31.2% reported that they had ever had a mammogram, as compared to 40.0% of White women ($n = 5524$; $OR = 0.68$, 95% C.I. = (0.57, 0.81)). A logistic regression model of mammography utilization was estimated in which the predictors were race, age, income, education, and a set of variables representing knowledge and beliefs about various aspects of cancer and cancer prevention. With these factors controlled, the difference between African-Americans and Whites in mammography behavior were eliminated.

2. Determinants of Mammography Intentions Among Prior Screenees and Non-Screenees (Christopher Jepson and Barbara K. Rimer)

This study examined whether the factors influencing a woman's intention to have a mammogram differ for women who have had mammograms in the past (prior screenees) and for those who have not (prior non-screenees). The sample consisted of 405 asymptomatic women aged 50 to 74; 162 of these were prior screenees and 243 were prior non-screenees. Subjects participated in a survey in which they were asked about their intentions to have a mammogram in the future. A number of other survey items were identified, a priori, as potential predictors of intentions. This set of items was used to predict intentions separately among screenees and non-screenees. For each group, these variables were entered into a linear regression model of intention, and backwards elimination was used to remove variables not contributing significantly. Among prior non-screenees, the final model was highly predictive of intention, explaining nearly half of the variance ($F = 18.35$, $p < .0001$, $R^2 = .46$). Among prior screenees, by contrast, the final model explained only about one-seventh of the variance in intention ($F = 10.69$, $p < .0001$, $R^2 = .14$). Thus, at least with respect to intentions, there do appear to be substantial differences in the factors influencing prior screenees and non-screenees.

3. Determinants of Repeat Adherence to Screening Mammograms (Christopher Jepson)

This project consisted of two pilot studies for the purpose of testing materials and procedures for future research. In the first study, asymptomatic women aged 50 and over who were about to receive their first screening mammogram participated in two interviews, before and after the mammogram. In the second study, women who had had their first screening mammogram approximately 21 months previously participated in a single interview.

In Study 1, a total of 29 respondents completed both interviews. Among these respondents, 38% reported significant anxiety during the mammogram; 34% reported significant physical discomfort; 14% reported significant inconvenience; and 21% reported significant embarrassment. 48% said they definitely would get another mammogram next year; another 31% said they probably would, and 17% were unsure. Only one respondent said she probably would not.

In Study 2, a total of 155 respondents were recruited, of whom 51% had had another mammogram since their first one. Among those who had not, the percentages agreeing with various reasons for not getting another mammogram were as follows: Anxiety, 14%; pain, 8%; inconvenience, 27%; embarrassment, 8%; cost, 9%; concern about radiation, 25%; belief that annual mammograms are unnecessary, 13%; lack of recommendation or reminder, 8%; "I'd rather not think about it," 26%; and "I've simply never thought about it until now," 49%.

In summary, repeat adherence appears to be a problem in the population studied, and aversive experiences are reported by a substantial fraction of respondents.

D. Hypothesis and Objectives

The central hypothesis of this study is that in a population of women of comparable socioeconomic and educational background the African-American women will report lower rates of mammography utilization than White women. An auxiliary hypothesis is that this discrepancy will be at least partially accounted for by differences in social and psychological factors such as knowledge, beliefs, and social norms. Due to the lack of prior research on this population, however, no hypotheses are proposed concerning which specific variables will be important; the analyses addressing this question will be exploratory in nature. The information gained in this study will not only be valuable in and of itself but should also provide useful pilot data for future observational and interventional studies.

The objectives of this study are as follows:

- (a) To recruit and survey a randomly selected sample of African-American and White female teachers aged 40 and over from the School District of Philadelphia;
- (b) To describe knowledge, attitudes, and practices related to breast cancer and mammography in this sample;
- (c) To compare rates of mammography among African-American and White women of comparable socioeconomic status and health care access; and
- (d) To explore possible reasons for any racial differences in behavior.

BODY

A. Methods

Subjects

The study population is composed of female teachers aged 40 and over from the School District of Philadelphia. Participants were selected specifically from the Philadelphia Federation of Teachers union (PFT). This population consists of approximately 6700 individuals, of whom approximately 37% are African-American. Anticipating that there will be a difference in the adherence to screening guidelines between the age groups 40-49 and 50 and older (Champion, 1994), these two groups will be analyzed separately.

Procedures

Prior to the start of data collection, a list was generated by the PFT containing the name, address, and telephone number of each member of the population defined in the previous section. From this list, a sample of 1996 individuals was randomly selected. The PFT sent a letter to each individual in this sample, informing them of the study and urging them to participate.

At the start of Year 02, a package of materials (Mailing 1) was mailed to each individual in the sample, containing the following items:

- (a) A cover letter describing the study and asking the individual to participate;
- (b) The study questionnaire, including the Consent Form as its first page;
- (c) A second copy of the Consent Form for the respondent to keep;
- (d) A postage-paid return envelope.

As each completed questionnaire is received, it is logged in. Several weeks after Mailing 1, reminder telephone calls will be made to all individuals from whom a completed questionnaire has not yet been received. Their purpose will be to answer any questions the individual might have, to provide reassurance, and to explain the importance of every individual's participation. If the individual agrees to participate but has discarded her package, another will be sent.

Telephone calls are also made to any respondent who returns a completed consent form but whose questionnaire is filled out incompletely or incorrectly. The respondent is asked about the items in question, and if possible, valid responses are elicited.

For all individuals in the sample who do not complete a questionnaire, the final disposition of the telephone calls will be recorded (e.g., refused, no answer).

It is anticipated that the combination of PFT endorsement of the project and reminder calls will yield a satisfactory response rate (approximately 80%) in this population. Against the possibility that this does not occur, however, a subset of 100 individuals in the original sample will be randomly selected and targeted for intensive recruitment efforts. Individuals in this subset will receive the procedures described above, but if those procedures fail to result in a completed questionnaire, project staff will attempt to contact the individual in person at the school where she works, and if possible, arrange to complete the questionnaire together. The goal will be to achieve a completion rate of over 80% in this subsample. The responses of the respondents who received intensive recruitment efforts will then be compared to the responses of the remaining respondents in order to identify any sampling bias in the latter. As time and money permit, these efforts will be applied to the overall sample in order to increase the response rate as much as possible.

In order to verify the accuracy of respondents' self-reports of screening behavior, medical records will be checked for a subset of respondents. This subsample will consist of all respondents who report that their most recent mammogram was obtained at the Hospital of the University of Pennsylvania.

Materials

The constructs measured by the questionnaire are described below.

Medical history. Respondents are asked if they have ever had breast cancer or any breast problems that required an office visit with a surgeon or other medical procedures. Respondents who answer "yes" to either question will not be excluded from participation; however, respondents who have had breast cancer will skip certain parts of the questionnaire and their data will be analyzed separately. Respondents are also asked if they have ever had any other kind of cancer.

Health beliefs. Perceived susceptibility to breast cancer, perceived seriousness of breast cancer, perceived benefits of mammography, and perceived barriers to mammography are measured using scales developed by Champion (1991). Several additional items measuring perceived benefits and barriers are also included.

Mammography experiences are measured by a set of items asking the extent to which the respondent experienced the following in connection with her most recent mammogram: anxiety; inconvenience; physical discomfort; and other problems.

Reasons for not having a mammogram. Respondents who have not had a mammogram within the past 24 months are asked a set of questions concerning the reasons why they have not done so.

Subjective norms are measured for three sources: the respondent's doctor, family, and friends. Items follow the format suggested by Ajzen and Fishbein (1980),

Knowledge. Although several knowledge scales have been developed focusing on breast self-examination (Champion, 1991; McCance, Mooney, Smith & Field, 1990), no established scale specifically measuring knowledge of breast cancer and mammography and displaying adequate psychometric properties was found in the literature. A set of individual items taken from the work of various researchers, chosen to cover the major areas of knowledge that have been examined in the literature about breast cancer and mammography, are included.

Demographics. A set of standard demographic items (age, ethnicity, education, marital status, annual family income) are included.

Breast cancer in family and friends. Respondents are asked whether anyone close to them has ever had breast cancer.

Provider variables. Items measuring respondents' contact with the health care system (e.g., regular physician, receipt of mammography reminders or recommendations) are included.

Screening history and intentions. The following questions are asked: (a) How long ago was your most recent mammogram (0-1 year ago, 1-2 years, over 2 years, never); (b) How many mammograms have you had in the last five years?; (c) Where did you obtain your most recent mammogram?; (e) Do you intend to have a mammogram in the next 24 months? In addition, questions about clinical breast examinations and breast self-examination practices are included.

Data Analysis

Analyses will be carried out using the SPSS-PC statistical package. The percentage of individuals in the sample who complete the survey, and the percentages in the various categories of non-completion, will be calculated for the combined sample and for African-Americans and Whites separately. Descriptive statistics for all measures included in the interview, including reliability of multi-item scales, will also be calculated.

The central analysis of the study will be the determination of whether African-Americans and Whites differ significantly on any of the outcome variables (ever had a mammogram, recency of last mammogram, frequency of mammograms, and intentions). However, differences between African-Americans and Whites on all other measures will also, be examined. In

addition, the bivariate relationship of each predictor variable to the outcome variables will be examined, in the combined sample and for African-Americans and Whites separately.

For each outcome variable displaying a significant effect of race, an exploratory multivariate analysis will be conducted, for the purpose of examining factors that might account for the difference. First, a model will be tested consisting only of race plus demographic and medical history variables. If race still contributes significantly to this first-stage model, a second-stage model will be developed. In this model, demographic and medical history variables will be forced in, and any other predictor with a bivariate relationship to the outcome significant at $p < .10$ will be allowed to enter in stepwise fashion. As each new variable enters, the contribution of race will be examined to see if it is reduced or becomes nonsignificant.

Because of differences in recommended screening intervals for women aged 40-49 and 50-plus, the analyses described above will be performed separately on the two age groups.

Women with a history of breast cancer will be excluded from these analyses. If enough responses are received from such women, however, comparisons will be made with the responses of women with no history of cancer.

Year 01 Accomplishments

1. Meeting with PFT

Drs. Patterson and Jepson met with representatives of the Philadelphia Federation of Teachers (PFT) to discuss procedures for the study. The PFT provided us with a list of the names, addresses, telephone numbers, and Social Security numbers of all female teachers aged 40 and over; the list contained 6741 names. They agreed to send out a mass mailing to all the teachers we selected from the list, consisting of a letter describing the study and urging members to participate.

2. Meeting with School District

Dr. Patterson met with representatives of the Philadelphia School District. They agreed to send out a letter to all school principals informing them of the study and indicating the District's endorsement thereof.

3. Pilot testing

In June 1997, Drs. Patterson and Jepson carried out a pilot test of the survey questionnaire at University City High School. The first step was to secure the approval and cooperation of

the school principal and building representative. A time and place for the pilot test was arranged, and a letter of invitation was placed in the school mailbox of all female teachers aged 40 and over, asking them to participate. A total of sixteen teachers participated. Four additional teachers, recruited through personal contact with Dr. Jepson, also completed the survey instrument, bringing the total number of pilot respondents to 20.

The time needed by each respondent to complete the survey was measured; most respondents needed between 10 and 20 minutes, slightly less than expected. No respondents expressed any significant problems with the survey, although a few made suggestions for minor revisions. Drs. Patterson and Jepson reviewed all completed surveys, and based on this, a number of minor revisions were made; the purpose of almost all of these revisions were to make the instructions clearer so as to avoid invalid responses.

One other revision to the materials was made based on the experience of the pilot test. The original version of the letter inviting pilot respondents to participate described the study as having, as its primary purpose, the examination of differences between African-Americans and Whites in attitudes and behaviors concerning breast cancer and mammography. Both the school principal (a White man) and the building representative (an African-American woman) said that describing the project as a study of racial differences would be a "red flag" that would raise bad feelings and discourage many potential respondents. Thus, we revised both the letter of invitation and the Consent Form to reduce the emphasis on racial differences, while remaining as honest as possible about the study and its purposes.

4. Selection of sample

The original goal of this study was to collect data from 1188 respondents, as follows:

- 297 African-American women aged 40-49
- 297 White women aged 40-49
- 297 African-American women aged 50-plus
- 297 White women aged 50-plus

We expected the PFT database to have information on members' age and ethnicity. This would have allowed us to get four lists of names, one for each of the cells described above, and select an equal number of individuals from each list. Our plan was to sample 400 from each list; with a response rate of 75%, this would have given us 300 respondents per cell.

In fact, the PFT database has information on age but not ethnicity; thus, it was not possible to select, a priori, equal numbers of African-Americans and Whites. The proportion of African-Americans among female PFT members is estimated at 37%. Thus, in each age group, in order to end up with at least 297 African-American respondents, we would need to obtain data from $(297 \times 1/0.37) = 803$ women. Assuming a response rate of 75%, the total number of women in each age group we would have to sample in order to end up with 803

respondents would be $(803 \times 1/0.75) = 1071$. Thus, rather than 1600 as originally planned, the total sample would have to be $(1071 \times 2) = 2142$.

Clearly, the procedure outlined above would result in a larger sample of Whites that originally intended. Because of this, the number of African-Americans needed to achieve the level of power stated in the proposal is somewhat less than originally calculated. This fact, plus financial considerations (see #7 below), led us to decide upon a sample size of roughly 2000 instead of 2142.

By coincidence, the numbers of women in the two age groups were virtually identical. (In fact, the younger group consisted of 3548 women, which was 355 more than the older group. Because the younger group is composed of women aged 40-49, approximately 10% of them should have been 49 when the list was produced. This happens to be exactly 355 women. Because the survey was mailed approximately six months after the list was produced, about half of these 355 women should have turned 50 in the interim. Thus, the two groups should indeed be virtually identical in size at the time of the survey.) Because of this, we decided to select names at random from the entire list rather than stratifying by age. The random subsampling feature of the SPSS-PC software package was used to make the selection. Pilot respondents were excluded from the sample. We also decided to exclude certain categories of individuals who seemed likely either to: (a) be ineligible, (b) not respond, or (c) be left out of the comparison between African-Americans and Whites that is the central purpose of the study. The individuals thus excluded (totaling approximately five per cent of all individuals who had been randomly selected) were as follows:

- People whose first names seemed clearly male (e.g., Gary, Gerald);
- People whose first and last names seemed clearly Asian or Hispanic;
- People with no telephone number listed in the PFT database; and
- People who were not living in Pennsylvania, New Jersey, or Delaware.

After these exclusions, a total of 1996 women remained in the study sample.

5. Creation of database

The names, addresses, and telephone numbers of the 1996 women in the study sample were entered into a project database using Microsoft Access. Each woman was also assigned a four-digit study ID number. All information in the database was proofread for errors by checking it against the PFT list.

6. Hiring

In September 1997, Ann-Marie Walsh-Brennan was hired as Project Manager and Nancy Hodgson was hired as a Research Assistant.

7. Mailings

In early September 1997, letters were sent by the PFT to the 1996 women in the study sample (see #1 above). Letters were also sent by the School District to the principals (see #2 above). Year 01 ended with the first mailing of survey packets about to take place. A copy of the materials comprising this packet (i.e., the cover letter, Consent Form, and survey instrument) are found in Appendices A, B, and C.

The original Research Plan called for three mailings of survey packets. First, a packet would be mailed to everyone in the study sample. Then, after four weeks, a second packet would be mailed to everyone who had not yet responded. Finally, one week later, reminder calls would be placed to everyone who had still not responded, and a third packet would be sent to everyone who agreed to participate but had discarded their packet. It was expected that each mailing would consist of about half the number of pieces of the one before.

The larger-than-expected sample size (see #4 above) meant that the costs of copying and mailing the survey would be larger than expected as well. This problem was compounded by the fact that, due to an oversight, the budget for materials that appeared in the proposal was based on the assumption that the sample size would be 1000 rather than 1600. Thus, the budget allowed for the mailing of only $(1000 + 500 + 250) = 1750$ pieces. Because of this, we decided to eliminate the second mailing. That is, the revised procedure is as follows: Several weeks after the first mailing, reminder calls will be placed to everyone who has not yet responded, and another packet will be mailed to anyone who needs one.

One other revision was made to the procedure in order to reduce the cost of mailings. The original Consent Form stated that a copy of the form would be sent to everyone who returned a completed questionnaire. This, however, would have required a separate mailing. To avoid this, we decided to include a second copy of the Consent Form, for the respondent to keep, along with the survey questionnaire.

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APPENDIX A. Cover Letter to Potential Survey Respondents

[Date]

[First Name] [Last Name]
[Address]
[City], [State] [Postal Code]

Dear Ms. [Last Name]:

We would like to ask you to participate in a brief survey of attitudes and behaviors concerning mammography among female public school teachers aged 40 and over in the Philadelphia School District. Our primary goal is to examine the effect of factors such as age, ethnicity, and access to care on these attitudes and behaviors. We have chosen the public school teachers of Philadelphia to be our respondents because you represent a population in which other factors, such as income, education, and place of residence, are relatively constant; this makes it easier to assess the role of the factors we have chosen to examine.

Based on pretests, we expect that the survey should take, on the average, between 10 and 20 minutes to complete. Your responses will remain completely confidential, and we will not give out our mailing lists to any outside organization. Please read and sign the Consent Form that is attached to the enclosed survey, and return it, along with the completed survey, to us by October 21 in the postage-paid envelope provided.

We understand that you are very busy at this time of the year and we greatly appreciate your taking time out to help us. Our ability to draw valid conclusions from our data depends critically upon receiving responses from as many of the individuals we invite as possible. Thus, the information you provide will be essential to the success of this project. Thank you very much.

Sincerely,

Elizabeth Patterson, MD
Assistant Professor of Radiology
School of Medicine
University of Pennsylvania

Christopher Jepson, PhD
Research Assistant Professor
School of Nursing
University of Pennsylvania

APPENDIX B. Consent Form

***** Please read and sign this form before filling out the survey. *****

Title of study: Philadelphia Teachers' Mammography Survey

Location: University of Pennsylvania Medical Center
Philadelphia, PA

Principal Investigator: Elizabeth A. Patterson, M.D. (215) 662-6726
Assistant Professor
Department of Radiology
University of Pennsylvania Medical Center
Philadelphia, PA 19104

Co-Principal Investigator: Christopher Jepson, Ph.D.
Research Assistant Professor
University of Pennsylvania School of Nursing

Funding Agency: U. S. Army Medical Research and Materiel Command

This study is a survey of female teachers aged 40 and older in the Philadelphia School District. The main purpose is to look at women of comparable residence, education, and income, and see if there are any differences between them in their knowledge, beliefs, attitudes, and behaviors regarding mammography as a function of other factors such as age, ethnicity, and access to care.

In this study, we ask you to fill out a questionnaire and mail it back to us, along with this consent form signed by you, in a postage-paid envelope that we provide. We expect that the questionnaire will take, on the average, between 10 and 20 minutes to fill out. Your name will not appear anywhere on the questionnaire and your answers will be kept completely confidential. We have tried to avoid asking any particularly personal or sensitive questions, but you are free to choose not to answer any question if you do not want to. No one who is not on the staff of this research project will ever see any of your answers. A second copy of this consent form is enclosed for your records.

One of the questions we ask is where and when you had your last mammogram (if you have ever had one). For some women in this study, we will be checking medical records to see if their answers to this question are accurate. When we check the medical records, we will look only at the date of the mammogram; we will not look at the result or any other information.

If we have any questions about any of your answers on the questionnaire, we may call you in order to make sure we understand correctly.

Your participation in this study is voluntary. There is no penalty if you refuse to participate, and you may discontinue participation at any time.

(The following statement is required by law.) You are authorized all necessary medical care for injury or disease which is the proximate result of your participation in this research. The U.S. Army requires that this institution provide such medical care when conducting research with private citizens. Other than medical care that may be provided (and any other remuneration specifically stated in this consent form), there is no other compensation available for your participation in this research study; however, you understand that this is not a waiver or release of your legal rights.

If you have any questions about this study, please contact Dr. Patterson at the address and telephone number listed at the top of this sheet. If you have questions about research subjects' rights, please contact the Executive Director of the University of Pennsylvania Office of Research Administration at (215) 898-7293.

It is the policy of the U.S. Army Medical Research and Materiel Command (USAMRMC) that data sheets are to be completed on all volunteers participating in research for entry into the USAMRMC's Volunteer Registry data base. The information to be entered into this confidential data base includes your name, address, social security number, study name and dates. The intent of this data base is twofold: first, to readily answer questions concerning an individual's participation in research sponsored by the USAMRMC; and second, to ensure that the USAMRMC can exercise its obligation to ensure research volunteers are adequately warned (duty to warn) of risks and to provide new information as it becomes available. The information will be stored at USAMRMC for a minimum of 75 years. We will not give out your name, address, or social security number to anyone else.

If you agree to participate in this study, please **print** your name and permanent address, and sign your name, in the spaces below, and please have a witness do the same.

Your name/address (please print):

Name/address of witness (please print):

Your signature:

Signature of witness:

***** Please be sure to return this form along with the survey. *****

APPENDIX C. Survey Questionnaire

ID Number: _____

Philadelphia Teachers' Mammography Survey

A1. Have you ever had breast cancer? 1 [] Yes 2 [] No

(If you answered yes, please skip to Section C on page 3.)

A2. Have you ever had any problems with your breasts? 1 [] Yes 2 [] No

(If yes:) Did any of these problems require ...

a. An office visit with a surgeon? 1 [] Yes 2 [] No

b. Other medical procedures (ultrasound, etc.)? 1 [] Yes 2 [] No

Please indicate how much you agree or disagree with the following statements, on a scale of 1 to 5, where 1 means you strongly *disagree* and 5 means you strongly *agree*.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
B1. The thought of breast cancer scares me.	1	2	3	4	5
B2. Having a recommended mammogram will make me feel good about myself.	1	2	3	4	5
B3. It is extremely likely that I will get breast cancer in the future.	1	2	3	4	5
B4. Breast cancer can be cured if found early enough.	1	2	3	4	5
B5. If I eat a healthy diet, I probably do not need to have a mammogram.	1	2	3	4	5
B6. When I think about breast cancer, my heart beats faster.	1	2	3	4	5
B7. Once I get a mammogram, I won't worry as much about breast cancer.	1	2	3	4	5
B8. I feel I will get breast cancer in the future.	1	2	3	4	5
B9. Mammograms have a high risk of leading to unnecessary surgery.	1	2	3	4	5

PTMS

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
B10. I am afraid to think about breast cancer.	1	2	3	4	5
B11. Having a mammogram will help me find lumps early.	1	2	3	4	5
B12. There is a good possibility I will get breast cancer in the next ten years.	1	2	3	4	5
B13. Once you have one mammogram that turns out normal, you don't need to have any more.	1	2	3	4	5
B14. Problems I would experience with breast cancer would last a long time.	1	2	3	4	5
B15. Having a mammogram will decrease my chances of dying from breast cancer.	1	2	3	4	5
B16. My chances of getting breast cancer are great.	1	2	3	4	5
B17. Getting regular mammograms will give me peace of mind.	1	2	3	4	5
B18. Getting a mammogram is one of the most important things a woman can do to keep herself healthy.	1	2	3	4	5
B19. Breast cancer would threaten a relationship with my boyfriend, husband, or partner.	1	2	3	4	5
B20. Having a mammogram will decrease my chances of requiring radical or disfiguring surgery if breast cancer occurs.	1	2	3	4	5
B21. If I had breast cancer my whole life would change.	1	2	3	4	5
B22. I am more likely than the average woman to get breast cancer.	1	2	3	4	5
B23. A woman doesn't need a mammogram unless she has a lump or some other symptom.	1	2	3	4	5
B24. Mammograms are harmless.	1	2	3	4	5
B25. Having a mammogram will help me find a lump before it can be felt by myself or a health professional.	1	2	3	4	5

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
B26. If I developed breast cancer, I would not live longer than five years.	1	2	3	4	5
B27. I'd rather not think about getting a mammogram.	1	2	3	4	5
B28. Mammograms are beneficial even when there is no history of breast problems in a family.	1	2	3	4	5
B29. If I had a mammogram I would feel worried or anxious while waiting for the results.	1	2	3	4	5
B30. If I had a mammogram I would feel reassured once I learned the results were normal.	1	2	3	4	5
B31. If I take care of myself, I can reduce my chances of getting breast cancer.	1	2	3	4	5
B32. There is little I can do to reduce my chance of dying of breast cancer.	1	2	3	4	5

* * * * *

For this next set of questions, think about the most recent mammogram you have had, and rate the extent to which you experienced each of the following things. If you have never had a mammogram, put a check mark here [] and skip to **section D** on the next page.

	None at all	A little	Moderate	A great deal
C1. Inconvenience:	1	2	3	4
C2. Anxiety:	1	2	3	4
C3. Physical discomfort:	1	2	3	4
C4. Other problems:	1	2	3	4

(If none, circle 1. Otherwise, specify problem below and rate it.)

PTMS

If you have had a mammogram in the last 24 months,
please put a check mark here [] and **skip to section E** on the next page.

If you have not had a mammogram in the last 24 months,
please answer the following questions.

Here are some statements about things that might keep women from getting a mammogram. For each one, please indicate how true that statement is of you -- not at all, a little, somewhat, or very much. Please give a rating for each statement.

I haven't had a mammogram in the last 24 months because ...

	Not at all	A little	Somewhat	Very much
D1. ... I've simply never thought about it until now.	1	2	3	4
D2. ... I'd be embarrassed about getting one.	1	2	3	4
D3. ... It would make me worry about breast cancer.	1	2	3	4
D4. ... It's too much trouble; I don't have the time for one.	1	2	3	4
D5. ... I'd rather not think about it.	1	2	3	4
D6. ... I'm concerned about the radiation from mammograms.	1	2	3	4
D7. ... Mammograms cost too much.	1	2	3	4
D8. ... Getting a mammogram would be inconvenient.	1	2	3	4
D9. ... Getting a mammogram would be painful.	1	2	3	4
D10. ... Any other reason? <i>(If none, circle 1. Otherwise, specify the reason below and give a rating.)</i>	1	2	3	4

E1. How do you think your regular doctor feels about you getting a mammogram?

1	2	3	4	5	9
Strongly opposed	Mildly opposed	Neutral	Mildly in favor	Strongly in favor	I have no regular doctor

E2. How about your family members?

1	2	3	4	5
Strongly opposed	Mildly opposed	Neutral	Mildly in favor	Strongly in favor

E3. How about your friends?

1	2	3	4	5
Strongly opposed	Mildly opposed	Neutral	Mildly in favor	Strongly in favor

E4. How important is it to you to do what your regular doctor thinks you should do?

1	2	3	4	9
Not at all important	Not very important	Somewhat important	Very important	I have no regular doctor

E5. How important is it to you to do what your family members think you should do?

1	2	3	4
Not at all important	Not very important	Somewhat important	Very important

E6. How important is it to you to do what your friends think you should do?

1	2	3	4
Not at all important	Not very important	Somewhat important	Very important

PTMS

F1. Could a woman have breast cancer without having any symptoms or feeling ill?

1 ☐ Yes 2 ☐ No

F2. Most lumps in the breast turn out to be harmless -- true or false?

1 ☐ True 2 ☐ False

F3. If a woman aged 50 or older does not have any breast problems or symptoms, how often should she get a mammogram?

1 ☐ Never
2 ☐ Less often than once a year
3 ☐ Once a year
4 ☐ More often than once a year

F4. Mammography can detect lumps in the breast that can't be felt -- true or false?

1 ☐ True 2 ☐ False

* * * * *

G1. Please check the highest degree you have completed:

1 ☐ Bachelor's 2 ☐ Master's

3 ☐ Doctorate 9 ☐ Other, specify: _____

G2. What is your age? _____

G3. What is your current marital status?
(Check one)

1 ☐ Married or living as married
2 ☐ Widowed
3 ☐ Divorced, separated, or never married

G4. Of the following income groups, which one would you say comes closest to your family's total combined income from all sources, before taxes, in the past 12 months? *(This information is requested for research purposes only and will be kept anonymous.)*

1 ☐ Under \$40,000
2 ☐ \$40 - \$59,999
3 ☐ \$60,000 or more

G5. What is your current employment status as a teacher?

1 ☐ Active 2 ☐ Retired

G6. What is your ethnicity?

1 ☐ White 2 ☐ Black/African-American

3 ☐ Hispanic 4 ☐ Asian/Pacific Islander

9 ☐ Other (*please specify*): _____

* * * * *

H1. Has anyone close to you ever had breast cancer? (*Check all that apply*)

1 ☐ No one 1 ☐ Mother

1 ☐ Sister(s) 1 ☐ Daughter(s)

1 ☐ Other relative(s) 1 ☐ Friend(s)

H2. Have you yourself ever had any kind of cancer other than breast cancer?

1 ☐ Yes 2 ☐ No

(*If yes:*) What kind? _____

H3. Do you currently smoke cigarettes?

1 ☐ Yes 2 ☐ No

H4. How many times during the past three months have you practiced breast self-examination?

☐ 0 ☐ 1 ☐ 2 ☐ 3 or more

H5. In how many of the past five years have you had a mammogram? (*Check one*)

0 ☐ None

3 ☐ 3 of the 5 years

1 ☐ 1 of the 5 years

4 ☐ 4 of the 5 years

2 ☐ 2 of the 5 years

5 ☐ All 5 years

H6. How long ago was your most recent mammogram?

1 ☐ I have never had one --> (*Skip to H-8*)

2 ☐ More than 24 months ago

3 ☐ 13 to 24 months ago

4 ☐ Less than 13 months ago

PTMS

H7. Where did you have your most recent mammogram?

H8. How likely do you think you are to get a mammogram in the next 24 months, on a scale of 1 to 10, where 1 means you definitely will not get one and 10 means you definitely will?

1	2	3	4	5	6	7	8	9	10
Definitely									Definitely
<u>will not</u>									<u>will</u>

H9. How long ago was your most recent breast examination by a health professional?

- 1 [] I have never had one
- 2 [] More than 24 months ago
- 3 [] 13 to 24 months ago
- 4 [] Less than 13 months ago

H10. Have you visited your family doctor or primary care physician in the past 24 months for any reason?

- 1 [] Yes
- 2 [] No (if no, skip to H-11)

(If yes:) Has he/she given you a referral for a mammogram in the past 24 months?

- 1 [] Yes
- 2 [] No

H11. Have you visited an OB/GYN in the past 24 months for any reason?

- 1 [] Yes
- 2 [] No (if no, skip to H-12)

(If yes:) Has he/she given you a referral for a mammogram in the past 24 months?

- 1 [] Yes
- 2 [] No

H12. In the past 24 months, did you receive any sort of reminder or recommendation to get a mammogram from any other health care provider?

- 1 [] Yes
- 2 [] No

Thank you very much for your participation!